Contribution to evidence in low-vision rehabilitation: Effects of CCTV training in visually impaired patients

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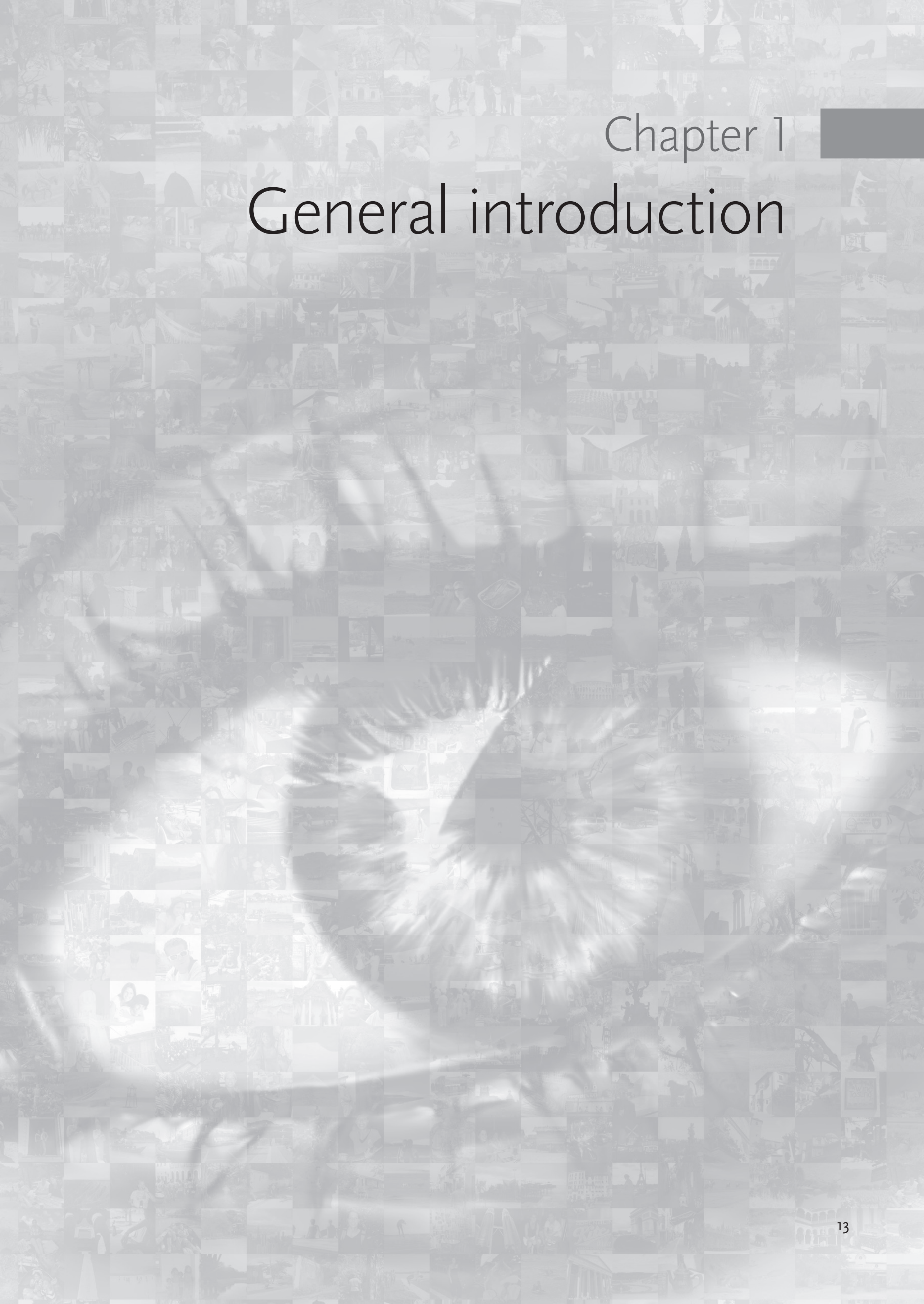

Chapter 1

General introduction

The main objectives addressed in this thesis are: the prescription of low-vision aids, the development of a standard training program in the use of closed-circuit televisions, and the evaluation of this training program in a randomized controlled trial using several outcome measures.

Definitions, prevalence and incidence of low vision

The definition for low vision and blindness as proposed by the World Health Organization (WHO), is often used in scientific research to describe the most detrimental categories of visual impairment. The WHO defines low vision as the best corrected visual acuity in the better eye <0.3 but ≥0.05 (Snellen notations), and/or visual field <20° around the central fixation point; blindness is defined as the best-corrected visual acuity in the better eye <0.05, and/or visual field <10° around the central fixation point.[1] Worldwide, various countries use other definitions for different purposes, for instance, as inclusion criteria for research, referral to rehabilitation, or as a criterion for health insurance. For example, in the USA and Australia, low vision is defined as the best corrected visual acuity <0.5, based on the required visual acuity for driving.[2] In the Dutch guidelines 'Visual impairment, rehabilitation and referral' is stated that patients with visual acuities <0.5 but >0.3, reading acuity <0.25, visual fields within 30° of fixation or other severe visual field defects (such as hemianopia), and relevant vision-related problems in daily living which cannot be addressed by ophthalmic interventions, and which can potentially be solved by visual rehabilitation, should be referred to low-vision rehabilitation services.[3] It should be noted, however, that decreased visual acuity and visual fields only partly determine the concept of visual disability. Other factors may also contribute to the patient's experience of the disability, such as contrast sensitivity, glare, and metamorphopsia, as well as personality characteristics and coping style.

In the year 2002, global data on visual impairment were gathered from 55 countries. The number of visually impaired persons was estimated to be over 161 million: 124 million persons had low vision and 37 million were blind.[4] Visual impairment and blindness are predominantly a problem of the least developed countries (about 80% of all visually impaired persons live here), where vision loss is caused by treatable or preventable conditions such as cataract, trachoma and onchocerciasis.[1] In contrast, in developed countries causes of low vision and blindness are most strongly associated with increasing age.[5] Therefore, the largest group of visually impaired persons in Western countries are the elderly, who may also have multi-morbidity, and functional and psychosocial limitations.[3;4] Although developments in the treatment of ophthalmic diseases are in progress, currently there is no cure for most of the age-related eye disorders.[6] Visual impairment in Western countries increases rapidly after the age of 65 (and blindness after the age of 85 years).[7;8] In the Netherlands, (where the studies described in this thesis were performed) out of the 16.4 million inhabitants in 2008, 311,000 were visually impaired and, of these persons, 79% was aged 65 years or over.[9]

It is expected that the percentage of persons with vision loss will increase by 18% to about 367,000 by the year 2020.[10]

The distribution of visual impairment is not only related to geographic regions and age but also to gender: females have a significantly higher risk of vision loss than males, even when corrected for age.[1;7;11] Visual impairment is most prevalent among residents of nursing homes and care institutions for the elderly, intellectually disabled persons, and among people aged 50 years or over living independently.[10]

Ocular pathology

In developed countries such as the Netherlands, the most common causes of visual impairment are age-related macular degeneration (AMD), diabetic retinopathy (DRP), glaucoma, and cataract. An exponential growth of over 40% in the prevalence of these diseases as a cause of visual impairment is expected between the years 2007 and 2020.[12]

AMD causes loss of central and detailed vision, as the macula (the central part of the retina) is part of the degenerating process. Two main forms can be distinguished. The nonneovascular (dry or atrophic) form affects about 85-90% of the patients with AMD, and is characterized by a gradual degeneration of the pigment epithelium and photoreceptor cells in and around the fovea, and by loss of choroidal capillaries. The hallmark of the nonneovascular form of AMD is drusen; other abnormalities include focal hyperpigmentation and geographic atrophy. The neovascular (wet or exudative) form is present in about 10-15% of patients. Any disturbance in Bruch's membrane (such as drusen) may lead to a break, allowing choriocapillaris and fibroblasts to perforate the inner aspect of Bruch's membrane causing growth of new blood vessels, which is referred to as proliferation or neovascularization. The new vessels are prone to leakage underneath the retina and the pigment epithelium, leading to a distorted image (metamorphopsia) and eventually scarring of the retina causing scotomata and severe vision loss. Medical treatment aimed at the exudative form consists of pharmacologic therapy (intravitreal injections with angiogenesis inhibitors), laser therapy (photocoagulation) for certain extrafoveal and juxtafoveal lesions, and photodynamic therapy (PDT) for subfoveal lesions with a classic component. Micronutrients (and lifestyle changes) may cause a risk reduction in rates of moderate vision loss in patients with intermediate AMD or advanced unilateral AMD.[13] However, treatment of the nonneovascular or atrophic form is generally not possible, leaving rehabilitation as the only option.

DRP is a complication of diabetes mellitus. The prevalence increases with duration of diabetes and age. Prolonged periods of high blood glucose levels (hyperglycemia) causes endothelial damage of the small blood vessels in the retina, which favour capillary occlusion and retinal nonperfusion, as well as decompensation of the endothelial barrier function causing serum leakage and retinal edema. DRP is classified into an early stage, nonproliferative DRP (NPDRP) and a more advanced stage, proliferative DRP (PDRP). Microvascular changes in NPDRP include microaneurysms, areas of capillary nonperfusion, nerve fiber layer infarcts, hemorrhages, hard exudates, arteriolar abnormalities, and dilatation and beading of retinal veins. NPDRP affects visual function by resulting in macular edema or macular ischemia. Diabetic macular edema can be treated with laser therapy, medical therapy (angiogenesis inhibitors or corticosteroids), and surgical therapy (vitrectomy and detachment of the posterior hyaloid). There is no treatment for macular ischemia. Progression to PDRP is characterized by proliferative processes on the disc or elsewhere on the retina, or the anterior segment. These processes may lead to vitreous hemorrhage and retinal detachment, due to growth of new and abnormal vessels into the vitreous cavity. Treatment is targeted at the prevention of these complications by management of blood glucose levels and blood pressure. Panretinal photocoagulation may induce regression of existing neovascular tissue and prevent progressive neovascularization. Intravitreal injection of angiogenesis inhibitors may reduce neovascularization on the short term, as may be necessary in case of neovascularization of the iris and anterior chamber angle. Vitrectomy is necessary in patients with nonclearing vitreous hemorrhage and retinal detachment.[14]

Glaucoma refers to a group of diseases that have in common a characteristic optic neuropathy with associated visual function loss, such as (gradual) visual field loss and decreased contrast and light sensitivity. Elevated intraocular pressure is one of the primary risk factors; however, a poor blood supply and a weakness in the structure or health of the nerve fibers may also play a role. Traditionally, glaucoma has been classified as open angle or closed angle, and as primary (no underlying cause) or secondary (underlying cause), combined mechanisms can also occur. To stop further damage to the optic nerve, treatment is aimed at the primary risk factor and consists of medication to lower the intraocular pressure, laser therapy (laser trabeculoplasty in open-angle glaucoma; laser iridectomy, gonioplasty or iridoplasty in angle-closure glaucoma) and/or surgery (trabeculectomy in open-angle glaucoma and aqueous shunt implantation in angle-closure glaucoma) to enhance the outflow of aqueous.[15]

Cataract is predominantly a problem of the aging eye. The gradual opacification of the lens causes blurred vision and complaints of glare. There are three main types of age-related cataract: nuclear, cortical and posterior subcapsular. Cataract is the leading cause of preventable blindness in the world, whereas cataract extraction with implantation of an intraocular lens is perhaps the most effective of surgical procedures, with a success rate of 99%. The lens will be fragmented and aspirated using phaco-emulsification (or in selected cases intracapsular or other extracapsular techniques are used), followed by the implantation of an artificial lens. In these patients low vision is usually caused by underlying ocular pathology or complications of surgery.[16]

In short, treatment modalities for visually impaired patients are limited and aimed at slowing down progression of the disease. Curation is almost never reached, except in cataract where other (post-operative) problems may cause low vision. Therefore, patients who suffer from vision loss caused by age-related conditions often rely on low-vision rehabilitation services.

Visual rehabilitation

Low-vision rehabilitation services

Visual rehabilitation aims to overcome visual disability,[17] to restore independence and to improve quality of life of visually impaired persons.[18] Two main types of low-vision rehabilitation are available in the Netherlands: monodisciplinary services (provided by optometrists) and multidisciplinary services (provided by regional rehabilitation centers for the visually impaired and blind). Patients can be referred to both services by ophthalmologists, general practitioners and other physicians. Furthermore, patients can contact these services on their own. Both services exist nationwide and the costs of these services are often reimbursed.

An optometrist assesses the patient's visual functioning and the problems experienced in daily living. The patients are then informed which low-vision aids might be suitable and receive instructions about their use. Optometrists are usually employed by commercial firms and are located in hospitals and/or in the community.

In addition, multidisciplinary centers (MRCs) offer outpatient rehabilitation services. Besides assessing the patient's visual function and prescribing low-vision aids, these centers provide training in activities of daily living (such as orientation and mobility training, cooking classes, computer training, etc.), advice on adaptation of the home environment, and individual or group counseling. Some centers also offer inpatient facilities, e.g., for adults with multiple disabilities and (pre)school children. In the inpatient centers, additional training programs are offered (such as job training), and training tends to be more extensive and/or intensive. Until recently, the regional rehabilitation centers were operated by three different organizations: Visio, Sensis and Bartiméus. The boards of Visio, Sensis and De Brink merged in 2008 to become the Visio-Sensis-De Brink group; however, since January 2010 they are known as Royal Visio. Similar low-vision care centers are available in the UK[19] and the USA,[6] as well as in other developed countries.

Low-vision aids

Problems with reading are a major threat to a person's social functioning and independence. Therefore, it is not surprising that among the rehabilitation needs reported by patients at low-vision rehabilitation services, reading problems are the most frequently mentioned.[20] Reading disability can (in part) be addressed by prescribing low-vision aids (LVAs). An LVA is any device that aims to optimize visual performance in order to overcome reading or other visual disability. There are two main types of LVAs: non-optical and optical devices. Examples of non-optical aids are large-print books and audio books, big-button telephones, talking clocks and watches, as well as clocks, timers, and watches with large, easy-to-read faces. Optical devices may be further divided into non-magnifying aids (such as glare protective devices) and magnifying optical aids.[21] The most suitable device depends on the person's individual needs and the remaining visual function. Other important factors in prescribing LVAs are level of magnification, ease of use, and cosmetic appearance. Common devices are: magnifiers (with or without illumination, hand-held, stand-mounted or on spectacles), telescopes (for reading and tasks which require longer working distances) and electronic devices (primarily closed-circuit televisions).[22] In the literature, magnifiers and telescopes are usually referred to as optical magnifiers and closed-circuit television (CCTV) as electronic vision-enhancement devices. Successful rehabilitation of low-vision patients with optical aids has been reported since 1974.[23]

Closed-circuit televisions

Although the technology to provide electronic images has been in development since the 1860s,[24] the use of a CCTV as a technical magnification device for the visually impaired was not described until 1959.[25] The first CCTVs were very simple: a black/white camera was vertically mounted on a stand and connected to a normal television. A powerful lamp was needed to provide enough luminance. The quality of the images varied widely. Since the 1990s, due to technological advances such as computer interfaces, color displays, and the development of smaller portable devices, CCTVs have become more widely available.[26;27] Currently available CCTVs can be classified based on the position of the camera and/or display into: stand-mounted, handheld, head-mounted and 'mouse' style CCTVs. They can also be classified based on the display: type of display (cathode ray tubes, liquid crystal displays or thin-film transistors), size of display (expressed in inch), position in relation to the camera (in-line, side-by-side or head-mounted) and electronic features (color options for fonts and background, contrast/luminance enhancement, contrast reversal and magnification range).[28]

In the present thesis, and in most studies, the abbreviation CCTV refers to stand-mounted CCTVs, as these are the most commonly prescribed.[22] Since, the abbreviation generally refers to surveillance devices, the term electronic vision-enhancement system has been proposed,[28] but has not yet been widely accepted. The stand-mounted CCTV consists of an X-Y table for positioning of the reading material, a display, and a camera with magnifying lenses.

CCTVs have many advantages over optical magnifiers; for instance, they enable higher magnification, contrast enhancement, image manipulation, reduction of aberrations, less critical focus, more natural working distances, better posture, binocularity and a longer duration of reading.[27;29;30] However, there are some disadvantages. CCTVs are relatively expensive and, most important, considerable effort is required to learn how to use the device. In the Netherlands, a considerable number of CCTVs are thought to be hardly used (or even returned to the provider) because patients find it too difficult to use the device. Watson et al. reported that 15% of all prescribed LVAs was abandoned after 12-24 months.[31;32] However, most patients continued to use their CCTV. A previous study on CCTV usage also reported continued use two years after provision; on the other hand, only 87% demonstrated effective use.[33] In general, the main reasons for abandonment of assistive devices are failure to improve function and quality of life.[34] Although studies have reported a positive psychological impact of CCTV devices in patients receiving a CCTV without training in its use,[35;36] training might contribute to more effective use of the device and, in turn, might improve function and quality of life.

Training in the use of closed-circuit televisions

Generally speaking, whenever a CCTV was prescribed in a Dutch rehabilitation center, training in the use of the device was also offered. However, training programs did not have a standard protocol and the effectiveness of the programs has never been proven. Although some exercise books on CCTV training were available in the MRCs, they were rarely used in daily practice. Therefore, the manner in which patients were trained, as well as the duration and number of training sessions, differed between the trainers (usually occupational therapists) and between rehabilitation centers. Since evidence-based practice is increasingly required by society (e.g., by government and health insurance companies), low-vision rehabilitation centers in the Netherlands aimed to standardize care and to obtain evidence on the effectiveness of their training programs, including training in the use of CCTVs. In the USA studies on CCTV training have mainly been performed in inpatient centers, whereas in the Netherlands (and in many other countries) training in the use of this device is offered through outpatient programs. In the Netherlands, a standard (outpatient) training program was lacking.

Previous studies provided only a brief explanation about the content of their training programs. Therefore, published information on an optimal training program was minimal. In the studies that were conducted, it was shown that training in the use of CCTVs improved reading speed as well as reading duration. However, the way in which reading speed was measured was not consistent, making the results difficult to compare; moreover, other aspects of training outcome were virtually unknown. In a recent review by Binns et al. on the effectiveness of low-vision service provision, 47 different outcome measures were identified; the authors stated that lack of consensus on the best approach hinders cross-study comparisons.[37] Therefore, it is important to use tests that are widely available and well standardized. An example of a well standardized method to measure reading performance, is the Radner Reading Charts. These charts use ‘sentence optotypes’, which are highly comparable sentences with respect to the number of words, word length, position of words, lexical difficulty, as well as syntactical complexity.[38] Furthermore, in addition to the important objective or clinical outcome measures (e.g., reading speed or acuity), in the last decade there has been increasing focus on assessing outcomes based on measures of ability and/or independence in performing daily tasks, and on measures of psychological status and perceived quality of life, from the patient's perspective. For example, patients with a good near visual acuity in the clinic (75%) are not always able to read small print at home (39%).[39] Moreover, mood and psychological status are closely connected with the ability to perform daily tasks, and an improvement in psychological status might be an expected consequence of low-vision rehabilitation even in the absence of a counseling/psychological component.[37]

Finally, most studies on CCTV performance are based on a within-patient design, whereas a randomized controlled trial (RCT) is more appropriate to evaluate the effectiveness of a rehabilitation program and to obtain an evidence-based training protocol. To our knowledge, only two RCTs have evaluated reading performance with CCTVs.[40;41] Moreover, these RCTs present contradictory results. For example, Faubert and Overbury found that the basic use of a CCTV, without specific training, did improve reading speed.[40] In contrast, Peterson et al. reported that familiarity with a CCTV had no significant effect on reading speed or task performance.[41] However, both trials had considerable limitations, the first trial concentrated on young healthy subjects, and the other concentrated on visually impaired patients who received only two minutes of instructions in the use of a CCTV. Furthermore, the latter study compared reading performance with a CCTV to reading performance with the patient's own optical magnifier.

Objectives and outline of the thesis

Due to demographic aging the number of visually impaired persons will increase considerably in the future, which will place more pressure on visual rehabilitation services and on social budgets. This increasing demand requires efficiently organized rehabilitation centers and optometric services. The studies presented in this thesis will contribute to low-vision rehabilitation by obtaining evidence-based knowledge on the effects of counseling, prescribing, giving instructions and other interventions with regard to the use of a CCTV by visually impaired persons.

First, the thesis focuses on the process of counseling and prescribing low-vision aids by the two types of low-vision services in the Netherlands, i.e., optometric and multidisciplinary services. As it is important to use standardized tests to make study data comparable to others, available reading charts were evaluated. The feasibility of a widely used chart, the Radner Reading Chart, was tested in a heterogeneous low-vision population. Then, a protocol is presented on how to instruct and train new users of CCTVs. A randomized controlled trial was conducted to test the effectiveness of the standard training program on various outcomes (compared to the delivery and usual instructions from the CCTV supplier). It was expected that, over time, patients who follow the standard instruction program will eventually have a higher reading speed, use the CCTV for longer and more frequent periods for a greater number of tasks, and have better acceptance of the use of the CCTV (and therefore an improved quality of life) compared to a control group.

In short, the main objectives of this thesis are:
1. To describe the process of prescribing low-vision aids to visually impaired patients;
2. To assess the reliability of a reading performance test: the Radner Reading Charts;
3. To develop a standard training program in the use of CCTVs;
4. To evaluate the effectiveness of training in the use of CCTVs, in terms of reading performance, vision-related quality of life and task performance in daily living.

Preceding chapters

Prescribing low-vision aids

In *Chapter 2* approaches to prescribing low-vision aids to visually impaired patients were investigated. Results are presented for patients referred to optometric services and patients referred to multidisciplinary rehabilitation centers. Closed-circuit televisions were frequently prescribed by both services to patients with moderate to severe vision loss.

Reliability of reading performance tests

In low-vision patients referred to visual rehabilitation services, vision loss is often caused by a variety of ophthalmic diseases. Therefore, *Chapter 3* explores whether the level of reading performance can be accurately obtained in this population with existing reading charts in the Netherlands. The reliability of repeated measurements with the Radner Reading Charts was investigated. The charts are also available in Spanish, English, Swedish, Turkish, Hungarian and French. They have an advantage over other national and international reading charts in that they use highly comparable sentences.

Main chapters

Development of a training program in the use of CCTVs and the design of a randomized controlled trial

Chapter 4 describes the actions undertaken to develop a standard protocol for visually impaired patients on how to use a CCTV. The final content of the protocol is presented. As the aim of the study was to provide an evidence-based training program, a randomized controlled trial was conducted to assess the effectiveness of training in the use of this device. Detailed information on the design of the RCT and outcome measures used is provided.

Evaluating the effectiveness of training in the use of CCTVs

In the following chapters, analyses based on the intention-to-treat principle (and additionally per protocol) were used to describe the effect of the training program. Patients were recruited between April 2008 and August 2009. Baseline measurements were performed from April 2008 to October 2009; follow-up measurements were performed after 3 months, untill January 2010. A treatment group and a control group were compared to objectify differences in reading performance (*Chapter 5*), perceived quality of life (*Chapter 6*),and task performance in daily living (*Chapter 7*).

General discussion and conclusion

Chapter 8 summarizes and discusses the results of the studies presented in this thesis, methodological limitations are addressed and recommendations are made for future research and clinical practice. The thesis is concluded with a summary in Dutch.

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